



Commentary

The pregnant pause: Engaging and involving public contributors in maternal health research

Joanne Rack^{a,*}, Vanora Hundley^a, Edwin van Teijlingen^a, Ann Luce^b

^a Faculty of Health & Social Sciences, Centre for Midwifery, Maternal & Perinatal Health, Bournemouth University, Bournemouth Gateway Building, St. Paul's Lane, Bournemouth, BH8 8GP

^b Professor of Journalism and Health Communication, Deputy Dean, Faculty of Media and Communication, Weymouth House W424, Talbot Campus, Fern Barrow, Poole, BH12 5BB



Introduction

PPI, or Patient Public Involvement, is a term used in healthcare as early as the 1970s (Ocloo et al., 2021) to describe research being conducted with or by members of the public. The term has gained significant popularity in healthcare research in recent decades and represents a shift in the way research is conceived, designed and executed. This contrasts with research previously done to, on or for members of the public and signals a critical change in the approach used especially in maternal health research where the involvement of a diverse range of people can change and enhance the quality, relevance and applications of research findings. The public contributors of PPI groups can include an extensive range of people, including patients, family members or carers, people from allied organisations, service users, and members of the general public who have an interest in research for other reasons. Participants bring their unique perspectives and experiences that can help to shape and inform the research process. This type of involvement ensures that maternal health research is grounded in the needs and preferences of those it aims to serve and grows a sense of ownership and investment amongst those who use the services but also those who provide them. PPI is an essential element for all maternal health endeavours.

In 2019, the National Institute for Health and Care Research (NIHR) issued a UK standard focusing on what "good public involvement" looks like. This framework supports six principles: inclusive opportunities, working together, support and learning, communications, impact, and governance (National Institute of Health Research 2024a). These principles have been adopted widely in the UK and beyond. Resulting in

guidelines and the ongoing development of resources for including PPI in research. These invaluable resources support and enable researchers to engage in this essential domain (VOICE 2024; Royal College of Obstetricians and Gynaecologists 2024).

Despite these advances, critical examination of published research about the process of PPI show a gap in transparency related to the contributions of PPI members and also reveals that the quality of reporting on PPI practices varies greatly (Fergusson et al. 2018). A 2014 scoping review found that there was limited evidence about the extent of PPI reported in the studies related to maternal health research (Pandey et al. 2014). To support researchers, the NIHR has produced an infographic that illustrates how PPI involvement should be woven throughout the research cycle (Hoskins 2024). By encouraging transparency and consistency in PPI practices, an understanding of the evidence can be strengthened, making it more compelling and easier to implement findings into clinical practice, ultimately improving maternal health outcomes.

Collaborative approaches to women's health research

PPI offers rich lived experience perspectives that aids design and mitigates biases inherent in research. It is responsive to the needs of women and aligns with the Women's Health Strategy for England which emphasises accessibility and diversity research participation (Atkins, Victoria 2024). The collaborative nature of the relationship empowers contributors to become invested and share and develop skills and expertise at various points across the research cycle. This echoes grass roots women's health movements and second wave feminism which

Acknowledgements: Dr Latha Vinayakarao MRCOG, MRCPI, PGCME, Consultant Obstetrician with a special interest in Maternal and Fetal Medicine, University Hospital Dorset NHS Foundation Trust, Poole Hospital, Longfleet Road, Poole, Dorset, BH15 2JB.

* Corresponding authors

E-mail addresses: jrack@bournemouth.ac.uk (J. Rack), vhundley@bournemouth.ac.uk (V. Hundley), evteijlingen@bournemouth.ac.uk (E. van Teijlingen), aluce@bournemouth.ac.uk (A. Luce).

<https://twitter@JoanneRack> (J. Rack), <https://twitter@VanoraHundley> (V. Hundley), <https://twitter@EvanTeijlingen> (E. van Teijlingen), <https://twitter@stann2> (A. Luce)

<https://doi.org/10.1016/j.midw.2024.104279>

Received 10 November 2024; Received in revised form 25 December 2024; Accepted 30 December 2024

Available online 6 January 2025

0266-6138/© 2025 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

speaks to the underrepresentation of women in health research, promoting equity, diversity and inclusion (EDI) (Nichols 2000; IGNITE 2024).

The ethical imperative of including public contributors in maternal health research can also be considered a human right (Stuttaford et al. 2017). As midwifery researchers and clinicians, we are responsible for ensuring that women and birthing people are involved in designing, exploring, discovering, and in knowledge mobilization of health and social care research (Hoskins 2024; Green 2016). Unfortunately, this level of involvement has not yet been realized within the midwifery and maternal health research community. To date, only modest acknowledgments of the significance and contribution of PPI have been made, suggesting a need for more robust frameworks (Perry and Mullins 2023).

Midwives are evidence-based practitioners, a principle built into our philosophies, models of care, and codes of practice (International Confederation of Midwives 2024). This philosophy emphasizes the need for integrating PPI into maternal health research to enrich the development of healthcare practices that go beyond patient satisfaction and provide key insights that can inform policy decisions and highlighting healthcare disparities ultimately resulting in the improvement of health outcomes for women and their families.

Cultivating evidence-based practitioners is a cornerstone within healthcare education programs (Lehane et al. 2019) this only serves to emphasize the importance of integrating PPI into the broader objectives of maternal health research. Public involvement strengthens the knowledge mobilization and translation aspect of maternal health research by adding weight to the quality of funding applications by allowing greater depth and subtle differences in perspectives to be incorporated into research findings, benefits are gained by those who the research is meant to impact the most. These insights ground the research in real-world experience increasing the relevance and impact for clinical practice and policy formulation. By incorporating this approach into all maternal health research, health care services can become more responsive through the influencing affect PPI has on the design and delivery of health services and subsequent tailored interventions.

Challenges and innovations in maternal health PPI

Maternal Health PPI presents unique challenges due to the transient nature of pregnancy. Unlike chronic disease research, which allows for longer term engagement, pregnancy is time sensitive and necessitates different approaches. Goodwin et al. showed how combining PPI activities with those that pregnant women prioritised, for example exercise and prenatal education (Goodwin et al. 2021). This demonstrated mutual benefits and maximized engagement. Models like this show how research can successfully engage and motivate pregnant populations who are eager to share their experiences and improve services.

Problem or Issue	What is already known	What this paper adds	Implications for practice
Limited reporting on Patient Public Involvement (PPI) within the field of maternal health research and midwifery.	PPI is essential in healthcare research. Guidelines and frameworks exist. Challenges for PPI involvement exist in part because of the transient nature of pregnancy.	A detailed account of implementing PPI in maternal health research. Practical strategies for recruitment and retention of PPI participants. Application of the GRIPP-2 framework in a maternal health context.	Midwifery researchers should prioritize PPI participation throughout the research cycle. Flexible approaches to PPI can enhance engagement and participation. PPI can improve the relevance and impact of maternal health research.
Lack of transparency in	Quality of PPI reporting varies	Transparent reporting of using	Improved reporting can

(continued on next column)

(continued)

Problem or Issue	What is already known	What this paper adds	Implications for practice
reporting of PPI research in maternal health and midwifery research.	greatly. There is limited evidence in the literature on the extent that PPI is used.	the GRIPP2 framework in maternal health research help to provide insight into informing and managing distinct groups within PPI.	enhance replicability and understanding of PPI in maternal health research. Dual PPI approach can provide more comprehensive perspectives.
Need for diverse representation in maternal health research.	Women's health research has historically lacked diversity. Barriers to equity, diversity and inclusion (EDI) exist.	Strategies for recruiting diverse populations into PPI in a maternal health context. Insights into engaging both healthcare professionals and public contributors.	Intentional creation of PPI participation can improve representation within maternal health research. Diverse PPI groups can help address health inequities.

PPI framework

We are using the GRIPP 2 short-form framework checklist to guide this discussion about PPI in maternal health and to demonstrate the way we used PPI in the Parentage Study. The GRIPP 2 short form is the more appropriate tool of the GRIPP tools and was developed to guide and formalize the process of PPI reporting in health research (Figure 1).

GRIPP SF framework for reporting on PPI (Figure 1)

Section and topic	Item
Aim	Report the aim of PPI in the study
Methods	Provide a clear description of the methods used for PPI
Study results	Outcomes—Report the results of PPI, both positive and negative ones
Discussion and conclusions	Outcomes—Comment on extent to which PPI influenced overall study. Describe positive and negative effects
Reflections/critical perspective	Comment critically on PPI study, reflecting on what went well and what did not, so others can learn from this experience

(Adopted from Staniszewska et al. 2017) EQUATOR Network - Reporting Guidelines. Available from <http://www.equator-network.org/reporting-guidelines/>

PPI involvement in the parentage study

Our aim is to involve and embed potential service users and members of the public in research on advanced maternal age and risk perception/communication. We want the voices of women, birthing people, and healthcare providers to be heard and for them to influence this research through participation in the research cycle including developing interventions and planning of services and care.

Method

Integrating PPI into The ParentAge study began with understanding best practices and current trends using key documents and training from leading organisations such as the NIHR (National Institute of Health Research 2024a) and the Health Research Authority (HRA) (Health Research Authority 2024). Support and guidance that aligned the project with community standards and national PPI standards was provided by Bournemouth University's BU PIER department.

Building a collaborator network is essential to all PPI projects. It

lends credibility and validity to the work that is being done. Support to this project was given by participants recruited via Bournemouth University PPI team (BU PIER), Dorset maternity voices partnership (MVP) and wider county-based resources as well as through University Hospitals Dorset Foundation Trust (UHD) and the University of Southampton Primary Care Research Centre. Once the process for PPI was well understood by the research team an outreach strategy was developed.

Development of outreach materials

Several different materials were developed as part of the outreach strategy. These included digital posters, social media materials, email communications, and PowerPoint presentations. Initially, outreach was conducted via email to potential community agencies and partners to inform them about our project followed by sharing digital materials for online outreach.

Recruitment into PPI groups

Recruitment for the public contributor group was initiated through the local Maternity Voices Partnership (MVP) Facebook page. The response was positive, resulting in a group of nine participants with diverse experiences including miscarriage, stillbirth, fertility challenges, induction of labour, complications of pregnancy, and home and hospital birth. The age range was 40 to 46 with varying parities and education levels.

A second PPI group was established with health care stakeholders, including midwives and consultant obstetricians. This group was more challenging to recruit, a personalized approach in the workplace proved to be the most effective method of recruitment. Two obstetric consultants and one senior midwife have joined the group.

Establishing foundations

Public contributors

Prospective participants were invited to discuss roles and expectations about participation in the project. A variety of materials were available for them, from posters to a PowerPoint presentation and through direct conversations. We recognized from the outset that unlike other PPI groups in health, ours has an element of greater transiency as pregnancy is relatively short and the birth of a child adds elements of complexity into the lives of the participants. This means that sometimes their ability for ongoing contribution is more limited. We like to take the standpoint that PPI is happening with real people in their real lives. Our participants are welcome with their toddlers and new babies in arms. We are happy to work to accommodate them based on their needs because we value their contributions.

Creating a safe space for our PPI groups to share experiences and opinions and receive compassion and respect was prioritized. Fertility, pregnancy and birth are life altering journeys and with them come joy and loss, trauma, and empowerment. They encompass and embrace elements of the full spectrum of human emotion and experience. They are simultaneously about giving up and asserting control over physical, emotional, and spiritual experiences. People often feel very deeply about what they have experienced, and we want that passion and experience to be felt and heard through the research we are conducting. Communication that fosters engagement and respect is at the forefront of our approach to PPI.

Facilitating discussion

Initial meetings were aimed at explaining PPI's purpose and explaining the research project. The ParentAge study is particularly interested in the experiences of our participants related to risk communication, perception of risk and engagement with health care

services for AMA women. Our initial discussions involved listening to the PPI experiences and perspectives helped to validate the research question and position it within the field. At this stage, the PhD research study design and data generation methods were prioritized, and questions were directed towards getting feedback in those areas.

Engagement and meetings

The initial meeting of the public contributors had been planned as a live workshop format. A brief PowerPoint presentation was developed to orient the participants to PPI guided research and to the PhD project itself. During this time the participants were given information about PPI as per (Oxford Medical Sciences 2024; Newman and Maddocks 2022) best practice standards for PPI discussion. Most discussions lasted an hour or more. Participants were asked to share their experiences and to identify areas where maternal health research should be focused.

To keep participants up to date between meetings, quarterly newsletter email communications are sent to all those who participate at various stages throughout the process. After the initial meeting, those interested in continuing to contribute were invited to provide feedback regarding study design, participant recruitment, design of information sheets, consent mechanisms and to review survey tools. Later, at the intervention design stage, they will be invited to provide input into the creation of an intervention and at the dissemination stage, they will be invited to participate in sharing the findings.

Professional group engagement

The PPI engagement of the professional group was similarly engaged to the public contributors. One-to-one conversations lasting 30–60 min were had, giving an orientation to PPI and an explanation of the research study. Conversations were focused on their experiences caring for AMA women, opinions on the direction of the research and feedback on study design.

Data protection and recognizing contributions in PPI

Data protection is an essential feature of health research, including PPI. Researchers must follow the General Data Protection Regulation (European Union 2000) ensuring participants understand their data rights and protections. Our PPI groups have been informed about how their opinions and experiences are being used within the context of our research.

Recognising participants' valuable time and energy is an important component of PPI. (National Institute of Health Research 2024b). Our PPI participants receive a gift card for each workshop or meeting that they participate in, acknowledging their commitment.

Insights to inform the research

Validation of research focus

Our PPI groups confirmed that investigating advanced maternal age and risk perception are highly relevant research areas. Our discussions highlighted the necessity of a multifaceted approach to address the issues and provide comprehensive solutions and tools useful for both clinicians and women.

Communication improvement

Both PPI groups commented throughout that there is a need for improved communication. Public contributors commented that the language used to describe AMA is stigmatizing. They cited needing informative discussions, involvement in decision-making and reinforcement of autonomy in health care choices as priorities, perceived lack of information provided and perceived inadequacy of information

and support as problems that repeated themselves throughout their care. They commented that the communication with their care providers was "abrupt" and that caregivers "didn't want to engage in conversations".

Both groups emphasized the importance of enhancing communication methods between staff and women to facilitate timely clarification and access to information. Health professionals agreed that optimizing pregnancy outcomes is a priority and voiced strong opinions that communication about risk and AMA should begin before conception.

Support for study design and methods

Our PPI groups spoke about the definition of AMA not being applied consistently both within the Trust where they were either working or receiving care. Public contributors reported differences within the care they received between different Trusts and from caregiver to caregiver. PPI participants told us that not uncommonly, there was "disagreement about which pathway" they were on and that plans were "unclear within the trust" with different care providers giving different advice about which care plan they should be on. The discrepancy in definitions and practice led the research team to develop and implement a national survey defining AMA in clinical practice. The Royal College of Midwives is supporting recruitment to this survey, and it has been distributed across the UK (Rack et al. 2023). Thanks to our PPI groups, we are now gathering data on how AMA is being defined in clinical practice, whether Trusts are developing their own clinical guidelines, and what guidance they are using to inform their practice.

PPI contributors were involved in discussion about the proposed research method using Corpus Assisted Discourse Studies (CADS) to analyse communication patterns in clinical interactions. This involves audio recording appointments. Feedback on this data generation method was positive among both health care provider and public contributor groups. Health care providers consulted larger groups of peers confirming the methods acceptability.

Public contributors supported using CADs to analyse communication and its impact on perception. They highlighted communication issues such as abruptness, lack of empathy, validating the use of audio recording to analyse real-life dynamics. Emphasising the importance of clear, empathetic communication and accessible information for informed choices. Many reported disengagement from health care providers, emphasizing the need for more supportive interactions. Women felt that the focus was on risk rather than optimization of positive outcomes, leading them to diminished hope and distrust.

The selection of surveys that will provide a quantitative assessment of autonomy and respect were made based on PPI feedback that emphasized the importance of these aspects, where women frequently reported feeling disrespected and lacking autonomy. Fear based language and power imbalances were identified as impacting decision making and autonomy negatively. Our public contributors consistently mentioned the need to feel valued, respected and having adequate time and information to support decision making.

Our health care professional public contributors agreed that a greater understanding of recommendations and best practice care pathways is needed as part of their updating and continued education to increase the provision of evidence-based care and consistent messaging of AMA best practice.

Conclusion

This paper has examined the essential role that PPI plays in maternal health research, highlighting benefits and unique challenges that it brings. Engaging strategies such as combining PPI work with activities that new parents and pregnant people prioritize addresses the transient nature of pregnancy and the demands parents face. The ParentAge study with its focus on personalized risk communication for AMA women, embraces this approach. Our PPI groups have provided essential guidance and validation for the research to date. Feedback from the groups

has highlighted the need for less stigmatizing language when describing AMA pregnancies and more empathetic and respectful communication strategies. Women's experiences of feeling inadequately informed and supported, coupled with reports of abrupt and disengaged interactions from caregivers, confirmed that how risk and care pathways are communicated is a key area of research. Both PPI groups support our study design and methods, validating the necessity, relevance and responsiveness of our chosen approach.

Looking ahead at the intersection between PPI and maternal health, continued effort to refine methodology and evaluate impact are necessary to progress the integration of PPI into health research. Further development of guidelines that encourage transparency for reporting PPI contributions and incorporating principles of working together including opportunities for inclusivity will pave the way for improved effectiveness of PPI in maternal health research, centring health care delivery around a more woman centred approach. PPI offers a model that fosters a feeling of ownership and personal investment for both the public contributors, health care providers and researchers alike, ensuring a collaborative effort that will ultimately benefit the target population. The ParentAge Study serves as a valuable model for future research in this field through its commitment to PPI and improved maternal health outcomes for all women.

Funding

This research received no specific grant from any funding agency, commercial, or not-for-profit sectors. This PhD is a Clinical Doctorate Studentship funded by Bournemouth University and University Hospitals Dorset.

Inclusivity statement

This manuscript primarily uses the term 'women' when referring to individuals who access maternity services or experience pregnancy. We acknowledge that not all individuals who become pregnant or give birth identify as women, and that gender-diverse individuals, including transgender men and non-binary people, may also require maternity care. Our use of gendered language reflects the terminology used in much of the existing literature and by many of our study participants. However, we recognize the importance of inclusive language in healthcare research and practice. We are committed to respecting and representing the diverse identities and experiences of all individuals who access maternity services. Where possible, we have used more inclusive terms such as 'public contributors' 'birthing people,' and 'pregnant people.' We encourage readers to interpret our findings and recommendations as applicable to all individuals who may become pregnant or require maternity care, regardless of their gender identity."

CRedit authorship contribution statement

Joanne Rack: Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Vanora Hundley:** Writing – review & editing, Supervision. **Edwin van Teijlingen:** Writing – review & editing, Supervision. **Ann Luce:** Writing – review & editing, Supervision.

Declaration of competing interest

None declared.

Acknowledgements

We would like to acknowledge Latha Vinyakarao, in her role as a clinical supervisor to this PhD and for her contribution to this manuscript.

References

- Atkins, Victoria, 2024. *Women's health strategy: 2024 priorities* [online]. GOV.UK. Available from: <https://www.gov.uk/government/speeches/womens-health-strategy-priorities-secretary-of-state-speech> [Accessed 20 Mar 2024].
- Fergusson, D., Monfaredi, Z., Pussegoda, K., Garritty, C., Lyddiatt, A., Shea, B., Duffett, L., Ghannad, M., Montroy, J., Murad, M.H., Pratt, M., Rader, T., Shorr, R., Yazdi, F., 2018. The prevalence of patient engagement in published trials: a systematic review. *Res. Involv. Engagem.* 4 (1), 17.
- Goodwin, L.D., Skrybant, M., Kenyon, S., 2021. Involving and engaging pregnant women in maternity-related research: reflections on an innovative approach. *Res. Involv. Engagem.* 7.
- Green, G., 2016. Power to the people: to what extent has public involvement in applied health research achieved this? *Res. Involv. Engagem.* [online], 2. Available from https://f5146caed8a556d1b4344a3e60314a0.r2.cloudflarestorage.com/scholarcy-library-ingestion-production/dafa6d15-3339-4118-9ded-59cfbdfdbabc4/s40900-016-0042-y.pdf?X-Amz-Expires=3600&X-Amz-Date=20240308T164623Z&X-Amz-Algorithm=AWS4-HMAC-SHA256&X-Amz-Credential=201ed02fc7ecc88dc772b53fdcdc8ff%2F20240308%2FAuto%2Fs3%2Faws4_request&X-Amz-SignedHeaders=host&X-Amz-Signature=b0f9216855afd3611f5d9bac2fb216c8fb8e65a8657fb1bb031e9b9e24bed9a5.
- Health Research Authority, 2024. *Public Involvement*. Health Research Authority [online] Available from: <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/> [Accessed 20 Mar 2024].
- Hoskins, L., 2024. *How to involve the public in knowledge mobilisation* [online]. NIHR Evidence. Available from: <https://evidence.nihr.ac.uk/collection/how-to-involve-the-public-in-knowledge-mobilisation/> [Accessed 20 Mar 2024].
- IGNITE, 2024. *Equality, Diversity, Inclusion • PPI Ignite Network* [online]. PPI Ignite Network. Available from: <https://ppinetwork.ie/our-work/equality-diversity-inclusion/> [Accessed 12 Mar 2024].
- International Confederation of Midwives, 2024. *Philosophy and Model of Midwifery Care* [online]. International Confederation of Midwives. Available from: <https://internationalmidwives.org/resources/philosophy-and-model-of-midwifery-care/> [Accessed 12 Mar 2024].
- Lehane, E., Leahy-Warren, P., O'Riordan, C., Savage, E., Drennan, J., O'Tuathigh, C., O'Connor, M., Corrigan, M., Burke, F., Hayes, M., Lynch, H., Sahm, L., Heffernan, E., O'Keefe, E., Blake, C., Horgan, F., Hegarty, J., 2019. Evidence-based practice education for healthcare professions: an expert view. *BMJ Evid. Based. Med.* 24 (3), 103–108.
- National Institute of Health Research, 2024a. *UK Standards for Public Involvement* [online]. Available from: <https://sites.google.com/nihr.ac.uk/pi-standards/home> [Accessed 12 Mar 2024].
- National Institute of Health Research, 2024b. *Payment Guidance For Researchers and Professionals* [online]. Available from: <https://www.nihr.ac.uk/document/s/payment-guidance-for-researchers-and-professionals/27392> [Accessed 20 Mar 2024].
- Newman, S. and Maddocks, L., 2022. *Patient and Public Involvement (PPI) welcome guide*. [online]. Available from: file:///C:/Users/jrack/Downloads/PPI%20welcome%20pack_March%2022.pdf [Accessed 10 Feb 2024].
- Nichols, F.H., 2000. History of the Women's Health Movement in the 20th Century. *J. Obstetr., Gynecol. Neonatal Nurs.* 29 (1), 56–64.
- Ocloo, J., Garfield, S., Franklin, B.D., Dawson, S., 2021. Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health Res. Policy. Syst.* 19 (1), 8.
- Oxford Medical Sciences, 2024. *Patient and public involvement* [online]. Available from: <https://www.medsci.ox.ac.uk/research/patient-and-public-involvement/patient-and-public-involvement> [Accessed 2 May 2024].
- Pandey, S., Porter, M., Bhattacharya, S., 2014. What women want from women's reproductive health research: a qualitative study. *Health Expect. : Int. J. Public Participation Health Care Health Policy* 18 (6), 2606–2615.
- Perry, A.G., Mullins, E., 2023. £25 and a biscuit: women's health research and public engagement in the UK. *Res. Involv. Engagem.* 9 (1), 120.
- Rack, J., Hundley, V., van Teijlingen, E.R. and Luce, Ann, 2023. *Defining advanced maternal age - a survey of NHS trusts*. [online]. Available from: <https://forms.office.com/Pages/DesignPageV2.aspx?prevorigin=shell&origin=NeoPortalPage&subpage=design&id=VZbi7ZfQ5EK7tfONQn-uM-g6TsFkUVOsBDUwzGFi15UNFRIRFJFTDI5UEdHN1dCRVBHVNVSk9QOS4u&analysis=true>.
- Royal College of Obstetricians and Gynaecologists, 2024. *Women's voices involvement panel (WVIP)* [online]. RCOG. Available from: <https://www.rcog.org.uk/for-the-public/rcog-engagement-listening-to-patients/womens-voices-involvement-panel-wvip/> [Accessed 12 Mar 2024].
- Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D.G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., Tysall, C., 2017. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 358, j3453.
- Stuttaford, M.C., Boulle, T., Haricharan, H.J., Sofayiya, Z., 2017. Public and patient involvement and the right to health: reflections from England. *Front. Sociol.* [online], 2 Available from <https://www.frontiersin.org/articles/10.3389/fsoc.2017.00005>.
- VOICE, 2024. *Voice: voice global* [online]. Available from: <https://voice-global.org/> [Accessed 12 Mar 2024].